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### Sugar

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# Sugar

Katrina Sotiropoulos



Medical records and information are updated and exchanged, medication is collected and sent to Club Med, and signatures are scribbled on forms that specify that the campers will not dose themselves unless instructed and overseen by a member of the medical staff. When they get to camp, the kids and their parents go through an extensive check-in process. Some of these kids have been dosing themselves for years, using their pumps to regulate their insulin. Many of them are in their teens and are rebellious and defiant to any and all authority. Quite a few of them continue to adjust their dosing without the proper supervision.

The result is dangerously low or sickeningly high blood sugars, often because they continue to be dosed by the medical staff at the normal dosing times. They also eat what they want when they want, sneaking snacks into the cabins and then only eating a plate of pasta and six cookies for dinner. And because they're old enough to pick and choose their own meals, they don't have an issue starting arguments with their counselors when they are asked to eat something with protein, or even a vegetable.

When their blood sugar does drop low or shoot high, campers never feel well. Their mood sours and sometimes they cry, wanting to go back to the cabin and nap. Or their energy skyrockets, and getting them to calm down and listen is nearly impossible. When this happens, the counselors then have to spend the remainder of the day chasing them around, waving ketone test strips in their faces only to have them swatted away, or listening to them sob into their

pillows in the cabin, sniffing about how awful they feel.

I am one of those counselors, usually assigned to the oldest or second oldest set of girls at camp. Their hormones are off the wall, and all they want to do is find a cute date to the camp dance.

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When I first arrive at camp, I have to check in. My not being diabetic, my check-in is quick and more like a "Hey, how are you?" rather than checking to see if I am old enough to handle my medication, who my doctors are, and so on. I receive my cabin assignment, hoping it's one of the newer cabins, but so far that hasn't happened.

My friend from high school comes with me, and we drive down to our cabin to begin the sweaty process of unloading our things. It's ten days out of the summer, and it's solely volunteer work. We are dressed in old T-shirts and shorts, our feet clad in flip-flops and ratty sneakers. Makeup stays in the car, or better yet at home. We make sure to rest up beforehand because soon sleep will become a novelty.

After setting up our things on the least saggy cot and swatting all of the spiderwebs from under the toilets and beneath the rafters, we gather in the mess hall to meet our fellow staff members. Many of us have done this before, while some are just doing it for service hours or to fulfill a degree requirement. I signed up in an attempt to fulfill an easy fifty service-hour credits while in high school. We range in ages from mid-teens to mid-to-late-sixties. But despite our varying backgrounds and appearances, at the end of the day, we're all here for the same reason: the campers.

We spend the next day and a half

Layout by Emily Goldberg. "Summer Camp" by Flickr user Sarah Joy, CC BY-SA 2.0: <https://www.flickr.com/photos/joybot/9015037562/>.

learning about diabetes, its causes and the various ways in which it's kept in check. We learn about what to do when blood sugars shoot up or plummet, and the dangers of both. I'm not sure I'll ever fully understand just how hard it is for a diabetic kid to live a normal life. Some are diagnosed months after birth, so all they know is this disease. Others may have been diagnosed in their early teens, so adjusting to their limits is an ongoing challenge.

When move-in day rolls around, we hang out in our cabins and wait for our campers. The process is slow: It takes the better part of a day for everyone to arrive and get settled. Still, it's exciting with the sounds of children yelling and laughing coming from their families as they move from the parking lot to check in. The whirl of golf carts whizzing by with stacks of suitcases and the campers' belongings fills the humid and hot air.

Occasionally a stray pillow flies off a cart, and screeching and arguing between the two drivers ensues. Each staff member's walkie-talkie receives a constant flow of instructions and directions from all over camp. The air feels electric with the mixed feelings of excitement, apprehension, and nervousness generated from tearful good-byes, bashful hellos, and ecstatic reunions. Energy surrounds the day with potential for the week—for the campers, their counselors, the medical staff, and all other volunteers.

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During my second summer volunteering as a counselor, I had five campers between the ages of thirteen and fourteen. One thirteen-year-old camper had never been to camp before and wasn't

too keen on the whole idea. She had recently been diagnosed with diabetes—only a year or two earlier. A newly emotional teen, she did not want to follow any of the rules. Her hair was dyed a dark red, her eyes were lined with black eyeliner, and she covertly used her phone when she thought I wasn't looking. She was quiet at first, but as she became more comfortable—coming out of her shell—she became difficult. She didn't listen to any of the counselors and would leave the cabin without telling anyone to go hang out with friends in another cabin.

She also had a lot of problems with her blood sugar levels. The campers were always dosed before and after meals, and then before bedtime. Depending on their levels at bedtime, they could even be woken up around 2 a.m. to check that they hadn't gone too low or too high. This girl always had levels that didn't match up with what she had eaten or how much insulin she had been given. The conclusion was that she had been dosing herself when she shouldn't have, causing the medical staff to become impatient with her. She felt poorly a lot of the time, which didn't help her attitude—or mine either.

As the week went on, her blood sugar levels began to improve a little, but the site where she received her insulin—pumped from a little box she carried around, down through a tiny tube into her body through a little needle—started to give her problems. When the infusion set ripped out the first time, I went with her to Club Med to have it changed. She whined a little, lifting up her shirt to reveal her bloated tummy, covered in faint bruises from past pump site spots. But then she silently found a healed section

of skin, puffy from the scar tissue that had begun to accumulate there, and attached a new infusion set.

Soon after we left Club Med, we began to talk. Of course we had talked before, multiple times, but at this point, she began to unload some of the baggage she had been carrying around, and her vulnerable side began to show. She told me what it was like to be diagnosed with diabetes, and how she had been so skinny before. Now she didn't like the way she looked in a bathing suit. She was only thirteen and already had a poor body image. We continued to talk, and I found out more about her, specifically how she knew how to dose herself—and how she did so at her discretion when she was at home. She had only had diabetes for a couple of years, but she was dedicated to trying to keep her blood sugar as stable as possible. Just from looking at her,

you wouldn't know this—that she was such a strong girl. She hadn't felt physically bad in a while and only wished she could continue to dose herself in the way she was used to.

The next day, her infusion set ripped out again. She was clearly upset about it, but calmly walked back to Club Med with me. This time, when she lifted up her shirt, she grimaced as she searched for a new patch of unblemished skin; the spot she had just used yesterday was pink, and a pinprick of blood sat welled in the tiny cut where the needle had been inserted. Snapping it into place with the inserter, she replaced her bunched-up shirt and we walked out. She was less chatty today, but I could tell she was thinking. I told her how brave I thought she was—how brave I thought everyone with diabetes at this camp was. She shrugged and



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said, "We have no choice, we have to be." She rejoined her bunkmates, and I watched her go, slipping easily back into a happier mood as her mind was distracted from what had just happened.

Later that day, while my cabin had pool time, she came up to me again, her face red and splotched, her mouth twisted downward. She showed me her infusion set, torn out for a third time in twenty-four hours, and so we went back up the hill towards Club Med, stopping only at the cabin to collect a new site needle. I asked her as we were walking if this happened a lot to her, and she said no. She said that she didn't usually have any issue with her infusion set staying intact, but it hurt her and she hated the bruising and swelling. I asked her if she had ever used shots, and she said for a brief period when she had first been diagnosed,

but her doctor thought it would be easier for her to use the pump. I asked her if she felt that was true, and she shook her head, her eyes filling with tears.

We walked into the cabin; the medical staff on duty looked surprised to see us back so soon. They weren't friendly, though, and clearly believed that my camper had been reckless with her site. She began to cry as she lifted her top for the second time that day, this time not even bothering to look for un-bruised skin. She inserted the infusion set, sniffing. I suggested to one of the doctors that maybe a note should be put in her file recommending that she go back to shots, that she hated the pump and wanted to try something else. All he said was that she could take this up with her doctor when she got home. I sat silently



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for the rest of the time we were there, thinking about the doctor's treatment of her, and the obvious pain that he was ignoring.

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Looking back now, I don't think the medical staff was doing a poor job of dosing any of the campers. I don't think that they weren't knowledgeable or that they didn't care. I don't even think that they wanted to upset any of the campers. But I do think that at least in the case of this girl, they had failed her. She was thirteen and vulnerable to a hateful body image, and lack of self-respect. She was vulnerable to thinking of herself as different in a bad way, and vulnerable to hurting herself in an attempt to fit in. She was vulnerable to hating her diabetes because it hurt her so much, and she hadn't been allowed to do what she knew would make her feel good. Yes, she was under eighteen, as were all of the campers. They had to do what their doctors and parents felt was right for dethem, but sometimes the opinions of the adults would overpower the opinions of the child and, though they might think they knew best, who knows one's body better than oneself? When a kid doesn't feel good, how can someone tell her that no, she is wrong, that she feels fine? Why should doctors, who know all the available options for receiving insulin and self-dosing, prevent a child from trying a new option or keeping with their known schedule, if it poses no harm to the child?

That challenges a previous statement pointing out that teenagers are rebellious and flighty, and their decisions are not always stable. So what would be the fair thing to do here? To take their voice away from them because

they aren't deemed emotionally stable enough? What if the adults were to listen to their voices, take into consideration their opinions on how they are feeling because maybe, just maybe, they are being truthful? In this day and age, the pressure to succeed is so high and demanding. Parents control all that they can for their children, often more than they should. They believe that they know what is best from their own experience, but how can their children really learn if they aren't allowed to have their own experiences and make their own mistakes?

That camper never came back. I've spent multiple summers there since, and have met and had to deal with so many other kids. But the memory of her story stays with me. I have had campers who have missed out on fun activities and hanging out with other kids because their daily routine at home wasn't the same as the camp-instituted routine; as a result, their blood sugar was all out of whack and they felt sick. Is it worth keeping all of the kids on the same schedule so it's easier for the medical staff to keep track of when they have been dosed, even if it makes many of the kids sick? I don't think so. It would be difficult to keep them all on a schedule, but not much more than getting all of their records and medications from their parents when they drop them off. It would be difficult, but not impossible.

Many of these kids have to mature faster than most in order to deal with their diabetes, so why not give them the benefit of the doubt if it might make their camp experience better, as well as their experience with their diabetes? I think we can afford to have a little faith.